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ABSTRACT

Research has shown that social support is psychologically beneficial to cancer patients, with support from families being especially important. A survey of the social support needs of 407 cancer patients and an in-depth interview study of 55 of those patients were conducted to examine issues concerning family support and cancer patients. Results from the survey demonstrated that, after accounting for prognosis, support was still related to patient well-being. The data suggest that family support is uniquely valuable to cancer patients. Patients in the second study reported that spouses were most helpful when they were physically present, expressed concern and affection, calmly accepted the illness, provided practical assistance, or were optimistic about the prognosis. Spouses were considered unhelpful when they were critical of the patient's response to cancer, minimized the personal impact of cancer, or expressed too much worry and pessimism. Similarly, other family members were considered most helpful when they expressed affection and concern, were physically present, or provided practical assistance; and unhelpful when they minimized the seriousness of the cancer or criticized the patient's response to the cancer. Future research should take a family systems perspective and examine ways in which family members (including the patient) mutually influence each other's attempts to understand and adapt to cancer. (NB)

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Family Support and the Cancer Patient

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The idea that interpersonal relationships influence psychological well-being has been advocated over the years by a diverse group of scholars including social and clinical psychologists, family therapists, and sociologists (e.g., Durkheim, 1951; Bowlby, 1969; Bateson, 1972; Minuchin, 1974; Reis 1984). Recently, this viewpoint has been transformed into specific propositions concerning how social support protects or promotes psychological or physical health, and increasingly, evidence for this relationship has accumulated (Cobb, 1976; House, 1981; Schaefer, Coyne, & Lazarus, 1981; Wethington & Kessler, 1986).

Investigations of social support processes among cancer patients, like studies concerned with social support generally, have found that social support is psychologically beneficial (Bloom, 1982; Dunkel-Schetter, 1984; Wortman, 1984). And the support, or lack thereof, received from spouses and families, in particular, appear to be especially important determinants of the patient's well-being following a cancer diagnosis (Jamison, Wellisch, & Pasnau, 1978; Smith, et al., 1985; Vess, et al., 1985).

While undoubtedly families are important resources to cancer patients and other victims, few would deny that family relationships and interactions are a mixture of both positive and negative qualities. In the context of social support, family members may fail to provide support, or may fail to provide the most beneficial type of support in the most effective manner.

We addressed issues concerning family support and cancer patients through two studies: The first, a survey of the social support needs of 668 cancer patients, and the second, an indepth interview study of 55 patients who were randomly selected from those who participated in the survey. First, I'll talk about results from the survey.

Family Support and Psychological Well Being (Results from the Survey)

Because a portion of the survey addressed the cancer support group experience, approximately half of the respondents were recruited from cancer support groups and half from general oncology practices. Approximately 80% of eligible patients contacted agreed to participate in this study.

They ranged in age from 21 to 89 with a median age of 58. The sample was disproportionately female (78% of the sample), and caucasian (93%). Subjects with all types of cancers participated.

With this data set we were able to test the hypothesis that family support is positively associated with psychological well-being, and that the family is an especially important source of support, perhaps more important then friends.

Because of missing data, the regression analyses that I will present shortly are based on a N of 407. This dramatic reduction in sample size (a loss of over 200) is primarily due to participants who indicated that they either had no family (n =90) or no friends (n=150). Thus, our analyses are based on people who have at least a few family members and friends who could provide support.

In these analyses, psychological well-being (the dependent variable) was measured by the Profile of Mood States (POMS). This instrument has been used widely as a psychological outcome variable in studies of cancer patients. Independent variables include: a prognostic index, a set of family variables, and a set of friend variables. I'll briefly describe each in turn. The prognostic index was derived from patient responses to questions designed to measure whether or not the cancer is currently in remission, whether there had ever been a recurrence, the extent to which the cancer limits daily activities, and patients' perceptions of their overall health status. The alpha of this index was .65. There are four family variables: The first we

called, Family Helpfulness, which is the average of two questions asking the patient to rate, on a five point scale, how helpful, first, spouse, and then, family have been with respect to the cancer. The second family variable called, Desire to share concerns and worries about cancer with family, represents patients' response to a question asking them to indicate, on a four point scale, the extent to which they wish they could more openly share their concerns and worries about cancer with their family. The third family variable is, Family Understanding, which is the average of two questions that measure the extent to which the patient believes his or her family understands what it is like to have cancer and has appropriate expectations for the patient following the diagnosis. The fourth family variable, Extent shares with family, is a single question asking patients to rate, on a five point scale, the extent to which they have shared, during the past 6 months, their cancer-related concerns and worries with their families. Finally, there are three friend variables which parallel three of the four family variables, they include: Friend Helpfulness, Desire to share concerns and worries about cancer with friends, and Extent shares cancer-related concerns and worries with friends. There is no parallel friend variable about expectations and understanding.

Since prognosis has been found to be related to individual well-being among cancer patients, it was entered as the first step in this multiple regresssion analyses.

Insert Table 1 about here

And, you can see in Table 1, prognosis is significantly associated with the POMS: explaining 14% of its variance. Next, the four family variables were

entered, as a set, in step two. The results indicate that, after accounting for the effect of prognosis, three of the family support variables are related to psychological well-being: family helpfulness, desire to share concerns and worries about cancer with family, and family understanding. Only Extent shares with family was not sigificantly associated with well-being. Overall, however, the family variables make a significant contribution to well-being, independent of prognosis: an additional 9% of the variance of the POMS total scale score was explained by the family variables. Thus, patients who believe their families are understanding and helpful, and who are satisfied with the amount of sharing between themselves and their family, demonstrate good psychological well-being as measured by the POMS.

As step 3, we entered variables indicative of friend support. In this way, we can see if support from friends, independent from family support, contributes to well-being. And you can see, here, friend support did not add significantly.

Next, we ran another equation, but this time reversing the order of steps 2 and 3.

Insert Table 2 about here

When the friend variables are entered in step 2, as a group they explain a significant portion of POMS variance. Interestingly, here too, as in the previous analysis with respect to family, helpfulness and desire to talk more openly are related to well-being, but the extent to which patients actually share their concerns and worries is not related to psychological outcome. In this equation, as predicted, the family variables make a significant contribution to well being, over and above support provided by

one's friends. The R^2 Change of .04, while not gigantic, is nevertheless significant.

The results presented so far demonstrate that, after accounting for prognosis, support is still related to well-being. Moreover, the data suggest that if one has good family support, support from friends may not be necessary. That adequate family support is good enough. And while support from friends is certainly beneficial, perhaps especially in the face of inadquate family support; family support, nevertheless, seems uniquely valuable to these patients.

Still many questions about family support and individual adjustment to cancer remain unanswered. Specifically, there is a need for a more fine-grained analysis of support transactions. Wortman (1984), in particular, has maintained that current conceptualizations of social support are too abstract to have significant practical benefits. It is simply unrealistic to believe that recommendations regarding the need to provide emotional support, information, or tangible aid are likely to yield behavioral change in potential support providers. Rather, what may be needed are more specific recommendations of exactly what kinds of actions are helpful and unhelpful. And this is what we attempted to do in the interview study.

When we initiated that study, we began with the assumption that support is benefical to cancer patients, but we wanted to know more about the details of such beneficial support transactions. This research addressed specific actions experienced as supportive or unsupportive by cancer patients from multiple social support providers: spouse, other family, friends, acquaintances, other cancer patients, physicians, and nurses. Today, I'll only talk about spouse and family.

This sample, as I mentioned earlier was drawn from the first survey

sample. It consisted of 30 women and 25 men with a median age of 54. Eighty-three percent were married, and 84% had children. Participants had been diagnosed or had sustained a recurrence (whichever was most current) an average of 3.2 years prior to the the interview. An independent oncologist reviewed medical chart materials and judged that thirty-six patients had a good prognosis, and the remainder (n=19) had a fair to poor prognosis. Patients with all sites of cancer participated.

Respondents were asked the same set of questions about each of the seven potential support providers. First, they were asked about the most helpful thing that each particular network member said or did to help the patient with his or her cancer. Next, they were asked about the most annoying or upsetting thing that each network member did or said.

Subjects' responses to these open-ended questions were coded into categories for data analytic purposes. Each case was independently coded by two judges, and the Cohen's kappa across all codes was .79. A third judge coded all questions in which the two original judges disagreed.

Spouse

First, lets talk about the spouse.

Insert Table 3 about here

In response to the question eliciting examples of helpful support provided by spouses, 35% of married patients indicated that their spouse's mere presence, regardless of what he or she did or said, was one of the most helpful behaviors. As one patient explained, "He was always there beside me, even when I was throwing up from the chemotherapy." This behavior, which we called "physical presence", however, appeared to be more helpful for good versus fair

to poor prognosis patients. Only 12% (n = 2) of the fair to poor prognosis patients versus 47% (n = 14) of the good prognosis patients spontaneously mentioned physical presence. And this difference was significant ($X2$ (1, N = 46) = 3.97, $p \leq .05$).

Expressing concern and affection was mentioned as most helpful by 33% of the married patients. In response to the question about helpful support from one's spouse, a man with head and neck cancer replied, "She just loved me."

Thirty percent indicated that their spouses' calm acceptance of the illness and its consequences was among the most helpful behaviors. A patient with quite advanced colon cancer explained, "I think the most helpful thing is that she never got ruffled by it. She just dealt with it, and carried on life as normal."

Other frequently mentioned helpful actions provided by spouses were the provision of practical assistance, and the expression of optimism about the patient's prognosis or ability to successfully live with the cancer. 20% of the patients interviewed mentioned each of these acts. Providing practical assistance, however, was more frequently mentioned by fair to poor prognosis rather than good prognosis patients: 50% of the fair to poor prognosis patients mentioned that providing practical assistance was among the most helpful spouse behaviors, while only 1 good prognosis patient mentioned this (X^2 (1, N =46) = 11.63, $p \leq .001$). Notice the low frequency of responses coded as "provided useful advice or information," and "permitted patient to openly express thoughts and feelings." We'll get back to this later.

When asked about negative experiences with spouses, 20% reported that being critical about the patient's response to cancer was particularly unhelpful.

Insert Table 4 about here

Here, patients typically gave examples of spouses who criticized their attitude (usually the spouse viewed it as too negative) or their health related behaviors, such as dieting or smoking. The following quote illustrates this:

> I would say it was his anger at my attitude. I might be okay for months, and then all of a sudden, I'm still not aware why, I feel insecure and depressed. He gets angry at my inability to mentally tolerate these things. So, of course I get angry at him because I keep saying to myself, `You dont know what its like to have this kind of disease until you do.'

Thirteen percent mentioned that they felt unsupported when their spouse minimized the personal impact of cancer--usually the spouse felt the patient was too preoccupied with the cancer, or from the patients' perspective the spouse did not seem to understand, and accept, their ongoing worry about cancer and its implications. A patient who had breast cancer explains: "He says I'm too focused on my illness, and that I should, you know, just go on about my life and not pay any attention to it anymore. I find that attitude hard to understand."

Then, on the other hand, 13% reported that expressing too much worry and pessimism about the cancer was the most unhelpful thing that their spouse did.

Other Family Members

Now lets talk about patients perceptions of other family members.

Insert Table 5 about here

In response to the question asking about the most helpful things that other family members did with respect to the patient's cancer, 40% mentioned expressions of concern and affection, 29% mentioned physical presence, and 24% mentioned the provision of practical assistance such as providing transportation, preparing meals, and providing postsurgical care.

In response to the question asking about family behaviors that were most upsetting, the two most frequently mentioned acts were about family members who minimized the seriousness of the cancer (18%), or criticized the patient's response to the cancer (13%).

Insert Table 6 about here

Finally, certain infrequently mentioned examples of helpful support are also noteworthy. First, providing useful information or advice was infrequently mentioned as a helpful type of support provided by spouse and other family members. This was not particularly surprising. Work by Dunkel-Schetter (1984) on breast and colon cancer patients, and Lehman, Ellard, & Wortman (1986) on the bereaved also found that advice giving was not particularly helpful.

Permitting patients to openly express their thoughts and feelings about cancer also was not freqently reported as a helpful type of support. Here we were surprised that creating an environment in which respondents could openly express their feelings was not mentioned more frequently. When I discussed this finding with friends who had cancer, most were surprised. Some suggested that maybe it wasn't mentioned often because so few respondents actually had spouses and families who allowed them to talk about their feelings. And, of course, this could be the case. But, when we asked patients what they wished

their spouse or family had done to help them deal with their cancer, very few mentioned anything that could be coded as allowing them to express their thoughts and feelings. Also, in the regression analyses presented earlier, the extent to which respondents shared their worries and concerns with spouse and family was the only family variable that was not associated with psychological well-being.

Conclusion

How can the results from this study be useful to those who are concerned about cancer patients and their families? First, these data indicate that we need to support families efforts to express their concern and affection. Although love, concern, and an appreciation of the seriousness of cancer was highly regarded, the data also indicate that such expressions, should be conveyed in a nonhysterical, noncatastophising way. Thus, family members need to be helped to strike a balance--to express concern about this most serious illness, but yet take it all in stride.

Families should also be encouraged to keep their advice and criticisms to themselves. My Aunt Jean, who has been married for over 50 years, claims that the secret to a good marriage is to be sensitive to each other's feelings and to keep your mouth shut. And it seems that her wisdom is relevant here. Clearly, criticisms, well intended or not, about how the patient is dealing with the cancer, and advice about how he or she should be dealing with it were experienced as unhelpful.

And finally, families of patients with a fair to poor prognosis should be helped to provide the practical assistance that is needed by these patients-- such as taking over certain chores and obligations, providing transportation to and from medical appointments, and providing nursing care. Assistance on a social structural rather than psychotherapeutic level is

called for here. Caregiving leave from work, publically subsidized home care services, and the like are the kinds of services that would help families provide practical aid to their relatives who have cancer.

One limitation of both the survey and interview study is that only the patient was assessed. Yet the giving and receiving of help is obviously a transactional process. So we naturally wonder about the spouse and family. What are their perspectives on the giving and receiving of support? Certainly, it is not easy to be an effective support provider, and thus we need to know what circumstances and recipient behaviors make it easier and more difficult to provide effective support to cancer patients?

Up until now, we've been discussing how spouse and family can be helpful to cancer patients, and have failed to ask who supports the spouse and family? Clearly, they, too, are under a great deal of stress and are in need of support and assistance. Although we never asked patients about how spouse and family were coping with the cancer nor did we interview family members, a participant in our study spontaneously expressed her concerns:

> They weren't there for my husband. I felt that the victim is perfectly well cared for, I think the victim's family needs the support. I really strongly believe that they are the ones who are left out virtually. They didn't give him what he needed.

Two recent studies (Cassileth, et al, 1985 and Keitel, Zevon & Rounds, 1986) suggest that adjusting to cancer may be more problematic for family members than for the patients. Cassileth and her colleagues, for instance, found that family members had lower scores on the Rand Mental Health Inventory, Emotional Ties subscale than did patients. This indicates that family members have less satisfactory socio-emotional relationships than do their patient-relatives. It is possible to imagine that family members are so

focused on helping the cancer patient, that they fail to support each other. And that other network members, also, are so concerned with the patient that they fail to help the patient's spouse and family.

The findings from this study and the questions raised, imply that further work in this area should focus on the multiple perspectives of family members. In the context of psychological adjustment to cancer, we need to look at patient, spouse, other family members and the ecology of their interactions. Future research on family support and cancer should take a family systems perspective, and look at the ways in which family members (including the patient) mutually influence each other's attempts to understand and adapt to cancer. Results from such studies can then be used to suggest specific interventions, both clinical and policy, to augment vital family support.

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Authors' Notes

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Table 1

Multiple Regression Analysis on Profile of Mood States (POMS): I

STEP		Ba	R2	R2 Change
1	Prognosis	-.38	.14***	
2	Family Helpfulness	-.12*	.24***	.10***
	Desire to share with family	.17***		
	Extent shares with family	-.00		
	Family understanding	.12*		
3	Friend Helpfulness	-.06	.24***	.006
	Desire to share with friends	.05		
	Extent shares with friends	-.06		

a Standardized Regression Coefficients

* $p < .05$

** $p < .01$

*** $p < .001$

Table 2

Multiple Regression Analysis on Profile of Mood States (POMS): II

Step		Ba	R2	R2 Change
1	Prognosis	-.38***	.14***	
2	Friend Helpfulness	-.13**	.20***	.06***
	Desire to share with friends	.18***		
	Extent share with friends	-.06		
3	Family Understanding	.10*	.24***	.04***
	Family Helpfulness	-.09 (p = .06)		
	Desire to share with family	.13*		
	Extent share with family	.03		

a Standardized Regression Coefficients

* $p < .05$

** $p < .01$

*** $p < .001$

Table 3

Patients' Perceptions of Helpful Behaviors from Spouse

Physical presence (just being there)	35%
Expressed concern, love or empathy	33%
Calmly accepted patient's cancer	30%
Provided practical assistance	20%
Expressed optimism about prognosis or patient's ability to live with the cancer	20%
Provided useful advice or information	9%
Permitted patient to openly express thoughts and feelings	2%

Table 4

Patients' perceptions of unhelpful behaviors from spouse

Critical of patient's response to cancer	20%
Minimized the impact of cancer	13%
Expressed too much worry and pessimism about illness	13%
Expressed little concern, love or empathy	11%

Table 5

Patients' Perceptions of Helpful Behaviors from OTHER FAMILY

Physical presence (just being there)	29%
Expressed concern, love or empathy	40%
Calmly accepted patient's cancer	13%
Provided practical assistance	24%
Expressed optimism about prognosis or patient's ability to live with the cancer	5%
Provided useful advice or information	7%
Permitted patient to openly express thoughts and feelings	7%

Table 6

Patients' perceptions of unhelpful behaviors from OTHER FAMILY

Critical of patient's response to cancer	13%
Minimized the impact of cancer	18%
Expressed too much worry and pessimism about illness	9%
Expressed little concern, love or empathy	9%